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SYMPTOM CONTROL ANALYSIS OF PATIENTS IN A PALLIATIVE CARE UNIT

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Background: In order to improve the quality of life of the patient and family it is essential to control symptoms, not only the physical ones, but also the psychological, social and spiritual. Objectives: To characterize the symptoms manifested by patients admitted to a palliative care unit and analyze the evolution of the symptoms of patients admitted to the palliative care unit (PCU) in the northeastern region of Portugal between 2009 and 2014. Methods: A quantitative, descriptive and retrospective study. Data collected through the care records and evaluation of the patient RNCCI [National Network of Integrated Continuous Care Units]. Statistical data were treated through Microsoft Excel and SPSS version 22.0 for Windows. The study encompasses the patient characterization data, the source, causes for requesting the diagnosis, assessment of the risk of falling according to the Morse scale, risk of pressure sores according to the Braden scale, the palliative care scale, symptom assessment according to Edmonton and pain assessment. Results: The patients were mostly male with a mean age of 73.5 years (± 11.4 years), married, retired and with under 6 years of schooling. The referral of patients is predominantly by the hospital and the diagnoses are mostly oncological. The number inpatient days were found to be 32.5 days on average and 83.7% of patients died in the PCU. Most patients have a high risk of falling and a high risk of pressure sores. In the palliative care scale and Edmonton symptom assessment the symptoms were found to be controlled in most patients. Conclusion: It was possible to observe that there is symptom control which is an asset for the quality of end of life of hospitalized patients and an improvement for the delivery of palliative care.

Keywords: Palliative care, Symptom control, Assessment.

Introduction

Over the years, countries have witnessed significant social changes including an aging population, increased longevity and incurable and progressive disease, which requires restructuring health systems

and providing appropriate responses to this new reality. Thus, there is a growing need for palliative care. (Associação Nacional de Cuidados Paliativos [ANCP], 2006). The Associação Portuguesa de Cuidados Paliativos (ANCP) (2015), considers palliative care an "active response to problems arising from prolonged, incurable and progressive disease in an attempt to prevent the suffering it generates and provide the highest quality of life possible for these patients and their families." Considering that the goal of palliative care is to achieve the best possible quality of life for patients and their families and due to the holistic nature of palliative care, it must be provided by a multidisciplinary and interdisciplinary with specific training (APCP, 2006). Improving quality of life is possible only through the relief of physical, psychological, social and spiritual symptoms (Twycross, 2003).

In recent years the number of chronic diseases has greatly increased, and there must be appropriate responses. Thus, palliative care "now constitutes the reference standard of care for patients with advanced chronic illnesses and their families" (Gonçalves, 2009, p.141). Neto (2000), considers that there are four main areas upon which the provision of palliative care is based: symptom control, communication, multidisciplinary teamwork and family support.

Faced with a progressive and irreversible disease, the main focus is on responding to patient needs, in order to control the physical, psychological, spiritual and social symptoms thereby achieving the maximum possible comfort and well-being for the patient and family (Santos, 2011). Carlo and Queiroz (2008) and Alves (2000) also point out that symptom control at all levels is the main aim of palliative care, because the final stage of life is made up of several changes to individuals' daily activities.

Twycross (2003) considers that the control of symptoms is summarized in five categories described as: evaluation, explanation, control, observation and attending to details. First, it is important to evaluate each symptom, knowing the cause, the underlying pathological mechanism, which has had no effect and the impact of the symptom on the patient's life. Then, the underlying mechanisms must be explained to the patient in simple terms before starting the treatment and the course of treatment must be decided with the patient. Later, the individualized treatment for each patient is implemented, assessed and monitoring the treatment and symptoms continuously and attending to every detail.

Given the uniqueness of each individual, the multidisciplinary team should have a common aim, which begins with knowledge of the clinical situation and leads to acceptance by the patient and family. Santos (2011) considers that the role of nurses is important from the acceptance of the diagnosis, assistance in how the patient/family live with the disease and support for the family before and after death.

Carlo and Queiroz (2008) consider primary symptom assessment crucial; however, continuous assessment is critical in order to start the approach to the patient and to know the efficacy of treatment. Symptom assessment instruments offer different benefits and are a key tool in symptom evaluation at all levels and consequently in obtaining effective therapeutic processes (Santos, 2011).

In this regard and in view of the above, the objectives of this research are to characterize the symptoms manifested by patients admitted to a palliative care unit and to analyze the evolution of the symptoms of patients admitted to the palliative care unit (PCU) in the northeastern region of Portugal. In order to achieve the proposed objectives data were collected, described and analyzed from the National Network of Integrated Continuous Care Units (RNCCI) IT computer application for the PCU under study.

Treating the terminally ill can only start after performing an evaluation (Twycross, 2003). The evaluation of symptoms should be performed often, accurately and thoroughly, without neglecting records and this is the entire team's responsibility. There are different symptom assessment tools; however, with regard to the evaluating symptoms, the patient should be the first evaluator (SFAP, 1999).

In order to know the symptom in detail, the team providing care must know the early onset of symptoms, the pathophysiological mechanism which underlies it, the effectiveness of previous treatments, factors that decrease/increase the symptoms and symptom impact on everyday life (Carlo & Queiroz, 2008).

Assessment tools can be divided into self-assessment tools, where the patient himself responds and hetero assessment instruments used when the patient cannot respond. Rating scales can still be quantitative, quantifying the intensity of the symptom or quality where the patient describes the symptom

(SFAP, 1999). Carlo and Queiroz (2008) also consider that the rating scales can be one-dimensional, measuring only the intensity of the symptom and multidimensional, evaluating physical and psychosocial aspects of symptoms. The authors also point out that there are obstacles to evaluating symptoms due to subjectivity or difficulty in defining some symptoms.

Symptom assessment tools have several advantages such as reduced cost and time of application. They can be applied by the patient or by third parties, allowing for a quick assessment. They can be used in either the hospital or at home. They constitute an essential tool for assessing symptoms at all levels and consequently for obtaining effective therapeutic processes (Santos, 2011).

There are various symptoms of symptom assessment, some simpler, being easy to use but unable to assess multidimensional aspects of the symptoms and other more complex and multidimensional ones. There are also many barriers to using some instruments, lack of validation, failure to evaluate multi-dimensional aspects of symptoms, applicability of difficulty in patients with cognitive disorders or difficulties in communication, multiple symptoms and a general debilitated condition of the patient (Carlo & Queiroz, 2008).

Methodology

Quantitative, descriptive and retrospective study. In order to characterize the symptoms manifested by patients admitted to a palliative care unit and analyze the evolution of these symptoms in patients admitted to a palliative care unit (PCU) in the northeastern region of Portugal from 2009 to 2014. The data were collected through a computer application from the records of patient care and assessment from the RNCCI.

The data were processed by Microsoft Excel and SPSS version 22.0 for Windows.

The study encompasses the patient characterization data, origin, causes for the request, diagnosis, assessment of risk of falls according to the Morse scale, risk of pressure sores according to the Braden scale, the palliative care scale, symptom assessment according Edmonton and pain assessment.

Assessment Tools

The Edmonton Symptom Assessment System - ESAS is recommended by APCP, so that it is the most widely used one in Portugal for assessing symptoms in palliative care. The scale is numbered from 0 to 10 and assesses nine symptoms, though it may evaluate more, where 0 represents the absence of the symptom and 10 the worst possible symptom intensity. Among the symptoms are: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, sense of well-being and shortness of breath (ANCP, 2006). The time required for this application is about five minutes and allows the predominant symptoms to be observed (Bausewein, Daveson, Benalia, Simon & Higginson, 2011).

The Palliative Care Outcome Scale (POS), consists of two parts, a questionnaire for patients and one for health professionals. Each part consists of 10 items, whose answers are numbered 0-4, following the Likert scale, including physical symptoms, psychological symptoms, the emotional and spiritual needs of the patient or family, practical concerns and an open question about the main problems (Palliative Care Outcome Scale [POS], 2015). Bausewein et al. (2011) consider that the average completion time is 6.9 minutes for the patient and 5.7 minutes for the healthcare professional, and follow up evaluations require less than four minutes to fill in. Palliative Care Outcome Scale - Symptoms (POS-S) is a scale of symptoms being, which like the POS, consists of two parts, a questionnaire for the patient and one for the healthcare professional. It includes 10 symptoms and more symptoms can be added, with Likert scale type responses from 0-4, where 0 corresponds to nothing/no effect and 4, unbearable/impossible to think of something else. It also contains two open questions about the symptoms that affect the patient more and that has improved or worsened more (POS, 2015). The POS-S can be used alone or it may complement the POS scale. There is a general version but there are also versions for patients with Parkinson's disease, or renal patients or with multiple sclerosis in the terminal phase (POS, 2015).

The Morse scale for the assessment of risk of falling includes items such as a history of falling, secondary diagnoses, support for ambulation, medication administration and/or intravenous heparin, walking ability, and mental state. Risk is classified as low if the score is between 0-24 points, average if the score is between 25 and 50 points and high if the score is greater than or equal to 51 points.

The Braden scale is used to assess the risk of pressure sores. According to the DGS [General Health Directorate] (2011), pressure sores are a health care indicator and a public health problem in Portugal, so that completing the Braden Scale to assess the risk of pressure sores is required. Risk classification can be high, if the score is less than or equal to 17 or low risk score is greater than or equal to 18.

For pain assessment we used the Visual Analogue Scale (VAS). It consists of a 10 cm long horizontal or vertical. The patient should place a cross or draw a perpendicular line on the line segment which represents the intensity of their pain. Then, the distance from the start of the line corresponding to zero and where the segment has been crossed is measured in centimeters. This provides a numerical rating to be entered on the record sheet (DGS 2003). A qualitative scale is divided into five parts: no pain, mild pain, moderate pain, severe pain and maximum pain. The patient should rate the intensity of their pain in accordance with these adjectives.

Five faces with different expressions are represented on the Faces Scale. The patient should rate the intensity of their pain according to the representation. The DGS recommends managing chronic pain in the elderly (DGS, 2010).

Procedures

Statistical data analysis, which were treated in Microsoft Excel and SPSS, were collected from a computer platform for monitoring application of RNCCI after a positive opinion from the Unidade Local de Saúde do Nordeste Ethics Committee (CE/AE 25/06/2014).

Socio-Demographic Characteristics of the Sample

In the period between 2009 and 2014, 375 patients were admitted, of whom 58.9% were male and 41.1% of females. The average age of patients undergoing care was 73.5 years (± 11.4), with a minimum of 28 years and a maximum of 101 years. The mean length of stay was 32.5 days (± 35.7 days), with a minimum of one day of care and a maximum of 210 days. Most patients were married (59.5%), 26.1% widowed and 8.3% were single. With regard to professional status, it appears that 85.4% were retired, 7.0% had an undefined or unknown employment status, 5.6% were employed and 2.1% were housewives.

Of the 375 patients under study, 256 only had primary or basic education, corresponding to the 4th/6th years of schooling respectively; 82 patients had no schooling or only had primary education and only 8 had postsecondary education (bachelor/master) and one had a doctoral degree. As for how patients were referred, 307 came from the hospital and 68 came from home.

From the RNCCI computer application the cause of the request is divided into seven categories: to provide rest for the caregiver in fragile situations, chronic diseases in acute exacerbation, need for continuity of care, need for vigilance and complex treatments, palliative care and need for patient/caregiver education. Each of these categories is subdivided into several items. None of the PCU patients' requests for admission were in order to provide rest for the caregiver. As for the class of fragile situations, this category was not applicable for 0.5% of the patients and in turn the main cause of request was dependence on Activities of Daily Life (ADLs) (93.3%).

Chronic disease exacerbation was not applicable to 7.2% of the PCU; 2.1% had Chronic Obstructive Pulmonary Disease (COPD), cardiovascular disease 1.9%, 1.6% had hepatopathy and most had no specification of chronic disease (87.2%).

The main reason for the need of continuous care was management of the treatment regimen (77.1%), followed by with 8.3% for treatment of wounds/pressures sores, other needs 8%, 4.8% for maintenance of devices, and 0.5% for rehabilitation. This category was not applicable for 1.3%.

In the 267 of the PCU patients, the need for complex treatment was not specified. For 56 patients this category did not apply, 32 were carriers of a nasogastric tube (NG) or percutaneous endoscopic gastrostomy (PEG), 11 had multiple pressure sores and 9 were post-operative patients.

As regards the causes for the request, in 73.3% the need for teaching the patient and/or caregiver was due to treatment regimen, followed by 8.3% in self-care, implementation techniques for 6.7%. It is unspecified for 6.1% and not applicable for 4%. Finally, 1.6% showed a need for teaching with regards to risky habits.

As for diagnosis of PCU patients, it was found that 97.3% patients had an oncologic diagnosis and only 2.7% were not oncological.

Of the patients with oncologic diagnosis, it was found that the most prevalent neoplasms were gastrointestinal disorders (28.5%), followed by hepatobiliary and pancreatic cancer (12.5%), lung (9.0%) prostate (7.9%), female genitalia (7.7%) and head/neck (6.6%). Skin cancer is the least present with 2.2% of the patients.

As for the outcomes of the PCU patients, 83.7% of the patients died. Other possibilities for outcomes were: discharge to long term and maintenance units (ULDM) (4.8%), home discharge (4.5%), discharge to another PCU (2.1%), discharge with the continuous care team (ECCI) response (1.6%), discharge to a nursing home (1.6%), discharge due to exacerbation (1.1%) and one patient was discharged for abandoning the PCU.

Results

Relative to recording risk of falling, of the 375 patients 242 had a risk of falling assessment, 99 had two and only 48 had three or more assessments. As regards the classification of risk of falling, in the three assessments average risk predominated with 59.5% in the first assessment, 53.5% in the second and 41.7% in the third assessment. No statistically significant differences were found in the comparisons made ($p>0.05$). In all of the patients assessed for risk of falling, it is greater in males but it stabilizes in both genders after the first 100 days of hospitalization.

The risk of pressure sores according to the Braden Scale was performed in 238 patients in a first assessment; 94 had a second assessment and only 43 had a third. For the three assessments high risk dominated, with over 75.5%, which corresponds to the second assessment, and a maximum of 79.1% which corresponds to the third evaluation. For the risk of pressure sores – Braden was only carried out with patients with two and three assessments. There are statistically significant differences in the comparisons made ($p\leq0.050$).

As for the risk of pressure sores, Braden was just carried out on patients who have 3 assessments (N=43). It was found that for the three assessments that risk of pressure sores is greater in males but it stabilizes in both genders after the first 100 days of hospitalization.

The scale palliative care (POS) consists of 19 signs/symptoms and in the coma and bedridden items, the possible answers are yes or no and controlled or uncontrolled.

The pain was controlled in 53.7% of patients in a first assessment, rising to 82.2% in the second evaluation and 77.8% of patients had controlled pain in the third assessment. For pain, significant differences between groups were found in the second and third evaluations through the binomial test.

In dysphagia, the percentage of patients with the symptom controlled was greater than 83.0% in the three assessments. Constipation was also a symptom which was mostly controlled in the three assessments, 69.0%, 77.2% and 74.1% respectively. For dysphagia and constipation, statistically significant differences were observed at the three stages of evaluation (value $p\leq0.050$).

The unspoken sign/symptom was largely controlled in the three evaluations and the uncontrolled percentage ranges from 11.8% in the first evaluation to 13.0% in the third assessment. In agitation, the controlled percentage is greater than 70.0% (second evaluation), with a maximum of 87.0% in the third evaluation. It is also worth noting that in the 2nd assessment of agitation, there are 100 evaluated patients and not 101 in the other symptoms. Furthermore, incontinence has an uncontrolled percentage higher than

the two previous signs/symptoms, that is, 49.8% at the first assessment, 52.5% in the second assessment and 27.8% in the third.

For the unspoken signs/symptoms and agitation statistically significant differences were observed in the three assessments through the binomial test; however, no statistically significant differences in the first and second evaluations between groups were found for the sign/symptom of incontinence. In the third assessment of this sign statistically significant differences were observed ($p \leq 0.050$).

For seizures, stench and drowsiness, it is worth noting that for the three assessments symptoms were mostly controlled with the maximum of 100% in the second and third evaluations of seizures and minimum of 82.1% for the first assessment of drowsiness. Through the binomial test, the three assessments of the signs/symptoms of seizures, drowsiness and stench statistically significant differences between groups were observed (value $p \leq 0.050$).

Similar to the previous signs/symptoms, in occlusion, cachexia and insomnia, for the three assessments the percentage of patients had greater than or equal to 81.2% (first assessment – cachexia) of the signs/symptoms controlled, with a maximum of 98.1% (third assessment – occlusion). It is noteworthy that in the second evaluation of occlusion 99 patients were assessed and 53 patients in the third cachexia assessment. Through the binomial test, statistically significant differences between groups three assessments of signs/symptoms were observed (value $p \leq 0.050$).

In anguish/depression, of the 229 patients assessed in the first evaluation, 138 had controlled symptoms and 91 patients were not controlled. In the second evaluation the majority (71 of 100 evaluable patients) showed controlled anguish/depression; and in the third evaluation of the 54 patients evaluated, 34 had controlled symptoms and 20 patients were not controlled. This profile has also remained for sore/ulceration, 164 controlled in the first assessment, 77 patients controlled in the second and 38 patients controlled in the third assessment.

Statistically significant differences between groups were observed in the first and second assessments for the sign/symptom of anguish/depression, through the binomial test; however, there were no statistically significant differences between groups in the third assessment. Statistically significant differences between groups were found ($p \leq 0.050$) for the sign/symptom sore/ulceration between groups in the three assessments.

With regard to haemorrhaging, the number of controlled patients is superior to uncontrolled for the three assessments (219 patients in the first evaluation, 98 patients in the second and 52 patients in the third). A statistically significant difference between groups was also found applying the binomial test ($p \leq 0.050$).

The percentage of uncontrolled signs/symptoms with respect to shortness of breath and nausea/vomiting in the three assessments ranged between a minimum of 5.6% (third assessment - nausea/vomiting) and a maximum of 18.3% (first evaluation - dyspnoea). For these two signs/symptoms, it appears that there is a statistically significant difference between groups.

On the possibility that the patient is bedridden and/or in a coma, it is worth noting that nearly all of the patients were not in coma (99.1% in the first assessment, 98.0% in the second and 100% in the third), but they were mostly bedridden (55.5% in the first assessment, 57.0% in the second and 55.6% in the third). Applying the binomial test to the sign/symptom coma, you can see that there are statistically significant differences between groups in the three evaluations; however, there are no statistically significant differences between groups in the three evaluations for the sign/symptom bedridden.

With regard to the fact that the patient is able to complete the evaluation, for the three assessments most of the patients were able to do so (83.2% in the 1st assessment, 76.9% in the 2nd assessment and 58.8% in the 3rd assessment). It is worth also stressing that the sample for this item for the first assessment is 192, 130 in the second evaluation and 97 in the last one. By applying the binomial test statistically significant differences between groups were observed the first two assessments, but in the last one there are no statistically significant differences between groups.

In the three pain assessments, a score of 2 relative to pain is prevalent, with 23.4% in the first assessment, 26.3% in the second evaluation and 28.9% in the third. Next is the pain score of 3 and 1,

respectively. The level of pain with the lowest percentage was scored at 10 in the first and third assessment, and a pain score of 9 in the second assessment with 0%.

With respect to fatigue, in the first evaluation level 3 fatigue prevails (20.8%), level 4 and 5 in the second evaluation, both with 20.3% and in the third assessment of fatigue 18.6% reported a level of 3. It is also possible to see that for both the symptoms (pain, and fatigue), a score from 0 to 5 prevails, meaning that the symptoms were either absent, mild or moderate.

For the three assessments of the nausea symptom, it was found that most patients had a score of 0 or 1. There were no patients who reported a score of 10 (worst case of the symptom). As for depression the predominant score was found to be between 2 and 5.

Generally speaking, with regards to the symptom of anxiety for the three assessments and for the majority of patients reported a symptom score between 1 and 5 while, for drowsiness there was a predominance of a score ranging between 0 and 6.

As for the appetite symptom, the score distribution for the three assessments was more dispersed. A score of 5 was predominant for the three assessments, and a score of 10 was the least present.

In the three assessments regarding the symptom of well-being the scores of 4, 5, 6, 7 and 8 predominated.

For the symptom of breathlessness, most patients were found to have a score between 0 and 2, which means that it was absent or slightly present.

Regarding the symptom assessment through the Edmonton symptom scale, it was only introduced in 2011 in the computer recording application. It also worth highlighting that 133 patients underwent a second evaluation and 97 patients underwent a third assessment.

No statistically significant difference in the comparisons were observed for the symptom of pain ($p>0.05$). There is, however, a statistically significant difference between the second and third assessments for the symptom of fatigue, $p\leq0.05$. For the nausea symptom, there is a statistically significant difference between groups for the second and last assessments. For the depression symptom a statistically significant difference in the comparisons was also found. In contrast, a statistically significant difference between groups of the second and third assessments ($p>0.05$.) was not found for the anxiety symptom. For the drowsiness symptom, a statistically significant difference was found between the second and third evaluation. Similarly, there is no statistically significant difference between groups of the second and third assessments for the appetite symptom, $p>0.05$. Nor was there a statistically significant difference between groups among patients who had second and third evaluations for the well-being symptom. Finally, $p\leq0.05$ for the symptom of shortness of breath, so that there is a statistically significant difference between the second and third assessments.

Pain assessment scores from 0 to 5. there were 340 first pain assessments, 161 patients had a second pain assessment and only 79 had a third evaluation.

In the first evaluation level 2 pain prevailed with 39.1%, followed by level 1 with 24.1%, level 3 with 20.6% with the lowest percentage being level 5 pain (2.4%). In the second evaluation, level 2 pain remained predominant (42.9%), then level 1 pain with 28.0%, level 3 with 19.9%, level 0 pain with 5.6%, level 4 with 2.5%, and as in the first assessment the lowest percentage belonged to level 5 pain with 1.2%. Regarding the third evaluation, level 1 pain had the highest percentage, followed by level 2 with 31.6%, level 3 with 21.5%, level 4 pain with 3.8% and finally level 5 with 1.3%. The Pearson correlation in pain assessment was only used with patients who had all three evaluations (N=79). A positive correlation was found between the first and the second evaluation and between the second and third assessments. However, there was no correlation between the first and third assessments.

Conclusions

According to the analysis described in this final report, it appears that the PCU population is mostly comprised of males, with a mean age of 73.5 years, mostly married, retired and with a level of education of 1 to 6 years of schooling and that the patients predominantly came from the hospital.

Regarding the main causes for admission to the PCU, there is dependence in daily life activities, management of the therapeutic regimen and the need to teach the patient/caregivers (treatment regimen). Noting the diagnosis of PCU patients, it is noteworthy that oncological diseases predominate (97.3%) in opposition to non-oncological diseases (2.7%). Analyzing, oncological diseases in particular, it appears that the most prevalent malignancies are gastrointestinal disorders (28%).

The average stay in the PCU is 32.5 days, noting that 83.7% of patients died in the respective unit. Thus, the high percentage of discharged patients is very low compared to deaths, indicating late referrals to the unit and the presence of very advanced progressive disease when the patient enters the PCU.

Analyzing the risk of falling (Morse Scale), the average level of risk was found to be the most prevalent and a high risk level was predominant risk for pressure sores (Braden Scale). It was observed that for the palliative care scale (POS), the symptoms show up predominantly controlled in the three moments of assessment. Symptoms with the highest percentage of uncontrolled response are incontinence, pain, anxiety/depression and constipation. Mostly, from the assessments carried out, the patients are bedridden and not in a coma.

Generally speaking, for all of the symptoms with the Edmonton symptom scale assessments, most patients were able to respond to the scale and had scores between 0 and 5, which allows us to deduce that the symptoms were absent, mild or moderate. Completing the Edmonton symptom assessment allows us to see swiftly, which symptoms are controlled and uncontrolled for each patient. Pain assessment is particularly important, and is considered the fifth vital sign, highlighting that for the PCU patients, the predominant level of pain was scored at 2 on a scale of 0 to 5 in the three evaluations carried out.

For proper evaluation of symptom control, it is essential to create a multidisciplinary team, especially nurses who are the professionals who spend the greatest amount of time with the patient/ family.

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